

**Alzheimer's Disease State Plan Task Force**  
**Meeting #4**  
**Thursday, May 27, 2010**

**Attendance**

Lisa Baron  
Glenda Meachum-Cain  
Julie Ballard  
Tim Dolan  
Deb Ellis  
Jean Leonatti  
Carroll Rodriguez

Joan D'Ambrose  
Joe Palm  
Lynn Carter  
Jerry Dowell  
Sen. Bill Stouffer  
Gwen Richards  
Lois Zerr

**Testimony from Professionals**

The Task Force heard testimony from various healthcare providers and associations.

**Missouri Healthcare Association**

- Representative: John Dolan
- Has read the compelling stories from the community forums but hopes the task force will consider the other side – the work that professionals are doing to serve persons with Alzheimer's.
- As an association, they provide a referral list of facilities that list out special care units and Alzheimer's specific care.
- There should be less debate between the types of care and which is better and more respect for the existence of each step in the continuum of care serving individual needs.
- While people want to keep their loved ones at home, there's not the entitlement money there.
- Many facilities want to provide special Alzheimer's care but there's just not the money or network.

**Missouri League of Nursing Home Administrators**

- Representative: Mike O'Day of Cedar Ridge Manor (Introduced by Cindy Wrigley, Executive Director of Missouri League of Nursing Home Administrators)
- The community forums reflected how overwhelming Alzheimer's disease is for the caregiver, but no one spoke for the experience of the person with Alzheimer's, and that is what the long-term care industry can speak to.
- Long-term care does the same thing that family caregivers do, and it needs to be part of the discussion.
- Currently, care is either private pay or paid for by the state. And while you will always want to be state-of-the-art, that comes through private pay.
- The best way to use current resources is through staff education and training.
- There is a lack of education. For example, there is no Alzheimer's training to become a CNA.
- While a secured Alzheimer's unit requires an application, Alzheimer's care is not part of the survey or emphasized in the semi-annual review.
- Long-term care is about culture change meaning that it is flexible and adaptable and can try things to provide good, meaningful care that works. For example, his facility started Camp

Cedar Ridge, where the children of staff can come to camp at the facility and interact with the older adults. The facilities are very regulated but they are not told how to do it.

- By empowering CNAs to make care decisions and care flowcharts and by listening to staff, his facility has been able to provide better care.
- Long-term care facilities can be a community resource to help caregivers, especially in rural communities, offering classes and informal support groups.
- The state of Missouri funds 60% of long-term care, and they have responsibility to use that money wisely.

#### *Questions and Comments from Task Force*

- Have you had any push back from residents regarding the children? No one has objected yet, but if they do, they will address it with the individuals who do not wish to participate.

#### Missouri State Medical Association

- Representative: Dr. Abhilash K. Desai, St. Louis University
- Dr. Desai's testimony is included below as submitted to the task force.

#### *Questions and Comments from Task Force*

- Joe Palm: Physician hours are not for the community; they are not easy to make for working families. Physicians should give back to the community and go into the community.
- Jean Leonatti: In a lot of the forums, we have heard that people cannot get a diagnosis. Can you submit a list from the Missouri Medical Association of what is happening in rural communities?
- Carroll Rodriguez: Do nurse practitioners get educated on diagnosis or dementia? Dr. Desai: No, they do not currently, but training could be two days long and then they gain confidence as they do it. It should also be required in schools.
- Lynn Carter: National Healthcare has a lot on workforce development, and this task force could be a link in that movement.
- Deb Ellis: How do we address the stigma? Dr. Desai: Have a person with dementia speak about their experience. There is a book called My Name is Not Dementia that collects stories from people with Alzheimer's.

#### Missouri Alliance for Home Care

- Representative: Mary Schantz
- Medicare covers very little long-term care. Medicaid does cover, but you have to be very poor in Missouri. Some people have veteran's benefits, but there is not much funding. The rest is private pay.
- Home care is not for everybody.
- Most people in the middle class are not eligible for Medicaid initially.
- The state should remove barriers to Medicaid, including division of assets for people under 63 and raising the minimum asset and income level for people living in the community.
- There is a lack of available resources, especially in rural communities. For example, adult day care in rural communities.
- End-of-life care: There needs to be training for workers to provide this care in the home and the community, and people need to receive these services early.

- Regarding quality, training is required by law and her association provides in-services, but we need it for all levels of care.
- Private duty is not regulated in the state, which is good for consumers because otherwise the cost would go up.
- The association is looking at healthcare reform for grant money for workforce training and to create a career ladder for aide workers.
- SharedCare is an available tax break for caregivers and a vehicle for training to family caregivers. We should get back to the original intent of the bill to give resources to caregivers by dusting off that training piece that has been underused.

#### *Questions and Comments from Task Force*

- Carroll Rodriguez: How do you improve mandatory training? Mary Schantz: They are pulling together a group to explore this issue.
- Tim Dolan: Is there a way for consumers to know about aide certification? Mary Schantz: A core curriculum exists, but there is no funding to get it out. Does not recommend private care unless it is done right with FICA pay, etc. Aides without FICA will grow old without Medicare and social security benefits. Aides are the backbone of care and so they are looking to build a career ladder with rate increases for aides and more accreditations.

#### Adult Day Industry

Representative: Amy Byergo, Director of the MU Adult Day Connection

- Medicaid reimburses for adult day services but now we are seeing sicker and sicker people because of the requirement that you must be nursing home eligible.
- Workers are required to have training, but there is no regulation about the consistency of that training. They are looking to create consistent training with the Alzheimer's Association.
- There are some services in rural areas but fewer, and they are not taking persons with dementia.
- The Adult Day Directory for Missouri comes out annually.

#### Missouri Association of Area Agencies on Aging (M4A)

- Representative: Carolyn McLaren
- Carolyn McLaren submitted written testimony to the task force, which is included below.

#### **Presentation on Community Forum Results**

- Jason Echols, practicum student at the Alzheimer's Association, presented the results of a qualitative analysis of comments from the community forums.
- Summary information is included below as submitted to the task force.

The Task Force broke into work groups.

#### **Quality Workgroup**

Quality Committee Focus Areas:

It was noted that the topic areas under Quality of Care/Professional Training from the Summary of Comments from Five Statewide Community Forums should be our priority as we make look at our focus and make our committee recommendations. These were discussed and are summarized in the following areas:

1) Training for Direct Caregivers –

There is a need for direct caregivers to receive training on caring for those with dementia. Ideas for this include to develop a standard core curriculum for hospitals, nursing homes, home health agencies, adult day care, etc. to use to train their caregivers. This could also be used in marketing their organization.

Hospitals – “Hospital Friendly Dementia Program” is a training that has already been developed by the St. Louis Chapter of the Alzheimer’s Association and is being shared across the country. This could potentially be used in hospitals across MO. The MO Hospital Association might be a partner in getting this training out along with corporations across Missouri.

Nursing Homes, Home Health, Adult Day Care – Discussed possibility of developing a webinar or web based training that could be accessed by all providers in the state, a basic curriculum in caring for people with dementia. HB603 already requires training to be done, but currently this training is not standardized and is often not followed up on by the surveyors. A training could be developed that to be resource for this training that is already required or it could be a standard curriculum that could be developed by the state in partnership with the Alzheimer’s Association. Maybe a rule change could be made to require use of a standardized curriculum.

- 2) Staffing Quality – To improve the quality of the staff and a way to monitor this, the suggestion offered by Mary Shantz and MO Alliance for Home Care, was a type of Career Ladder and database tracking system. An online registry could be developed that could be used by employers as well as consumers. This could also track levels of training in dementia and Alzheimer’s care if such a training curriculum were developed. An accreditation or certification in dementia care for direct care givers or some type of level system was discussed.
- 3) Medical Community – talked about potentially training the medical community through the hospital training mentioned above. Also the need of training for Nurse Practitioners as well as Physician Assistants might be an important piece in addition to the education of physicians. Also again discussed the use of the AD-8 diagnostic tool that is not copyrighted and could be used statewide.
- 4) Culture Change/Person Centered-Care –

Discussed embracing and promoting concepts of culture change and person centered care. There is need for training on these topics not only for providers but for surveyors as well. Good examples of this presented by MANHA today (Clydesdales, children in home)

### **Services Workgroup**

- Reviewed a draft of the services chart and took note of suggested changes
  - Julie Ballard can provide a list of facilities and maps of where they are located.
  - Carroll R. will add brief definitions of RCF, ALF, etc.
  - Glenda will check with hospitals on information about gero-psych units.
- The chart will be updated by Jean L. and emailed to the group for further comment and discussion.
- In moving towards the final report, the group will be clear that it is not advocating for any service over another. Persons with dementia will need to access services that fit their needs. Instead, the workgroup is advocating for quality across the continuum.

## Dr. Abhilash K. Desai's Testimony on Behalf of the Missouri State Medical Association

### DEMENTIA STRATEGY FOR MISSOURI

Abhilash K. Desai MD, Associate Professor and Director, Center for Healthy Brain Aging, Department of Neurology and Psychiatry, Division of Geriatric Psychiatry, Saint Louis University School of Medicine, 1438 S. Grand Blvd, St. Louis, Missouri. Tel: (314) 977 4884. Fax: (314) 977 4876. Email: [adesai@slu.edu](mailto:adesai@slu.edu)

"In all likelihood, dementia will become part of the shared experience of many friendships as we move toward a time in the not too distant future when 20 percent of the U.S. population is 65 or older. We need to find creative ways to nourish and sustain friendship even as memory and confusion mount. This can happen only if we reject our culture's view of dementia as an individual tragedy and commit ourselves to supporting one another in this new world of aging. To do this, we must accept that we are all vulnerable creatures gifted with the opportunity to build flourishing communities where everyone can live with meaning, joy, laughter, obligation, and fulfillment."

- Excerpt from the book titled "Aging Together: Dementia, Friendship, and Flourishing Communities" by Susan McFadden PhD and John McFadden MDiv; The Johns Hopkins Press. In Press.

Dementia costs the health and social care economy more than cancer, heart disease and stroke put together. Missouri has a unique opportunity to raise standards in the health and social care of people with dementia and their family and professional caregivers. I recommend the following six steps to achieve this.

### SIX STEP APPROACH

1. Prevention: Target population: High risk population (e.g., Inner city older adults with cardiovascular risk factors [diabetes, hypertension, smoking, obesity, hyperlipidemia], children of older adults with Alzheimer's disease and vascular dementia). Basis: Cardiovascular risk factors not only increase risk of stroke and vascular dementia but ALSO Alzheimer's disease. Intervention: Optimal control of these risk factors. Means: Mid-level practitioners (nurse practitioners, physician assistants) (to provide assessment and treatment) and nurses (to provide lifestyle modification education and motivational interviewing to improve compliance). Outcome: Reduced future incidence of Alzheimer's disease and vascular (stroke-related) dementias.
2. Public education: Goals: Reduce stigma and suffering stigma causes to persons having dementia and their family and to promote hope. Why? The evidence is clear that stigma and discrimination have a serious and detrimental effect on the quality of life of people who have dementia. ***Most people who have dementia are surrounded by a malignant social psychology which damages them as much or more than the actual brain damage.*** One thing we can certainly do a great deal about is changing these attitudes. By doing this, we can substantially benefit people who have dementia.

Patient 1: 'I knew anyway, what Alzheimer's is....he didn't say Alzheimer, he didn't want to say that. Early aging, that's what he said.'

Patient 2: 'I'm trying to guard that...the reputation, you know...don't want to be looked down on...like...don't want the feeling of being back in first grade or whatever....of

going in the other direction. Decreasing instead of improving....and [I have] inward anger.'

Physician: 'I get told all the time, "Please don't mention the A word". That's what it's called; it's called the A word. And I will be sensitive to that.'

When pressed, physicians often describe their diagnosis as 'memory problems' or 'thinking changes' instead of using a specific stigmatizing label. This behavior among physicians may serve to perpetuate the stigma and self stigma attached to dementia, as it can be reasoned that if professionals are unwilling to acknowledge the true status of the condition, then the person who has dementia and the wider public may continue to misunderstand the meaning of the term. This not only discourages diagnosis but contributes to a view of people with dementia that is wholly negative and damaging.

3. Proper / Accurate and timely diagnosis of dementia and comprehensive multi-disciplinary treatment: Target population: Adults older than 60 with memory decline or who screen positive using AD-8 screening tool. Intervention: Assessment of memory / cognitive decline. Means: Mid-level practitioners (nurse practitioners, physician assistants) under the guidance of primary care physicians to provide comprehensive assessment, accurate diagnosis of type of dementia and treatment recommendations; and nurses (to provide education about dementia and community resources [especially Alzheimer's Association]). Outcome: Improved quality of life. Why? ***There is strong evidence that improving the process through which people are diagnosed and widening access to a high level of support at a relatively early stage of the illness is beneficial.*** Being of use and giving meaning to life, security, and privacy, and self-determination are some of the areas that appear to have greater significance for people who have dementia. 90% of suffering of persons having dementia and suffering of their family members is preventable with early accurate diagnosis and comprehensive multidisciplinary treatment (patient, family members, physicians, neuropsychologists, nurse practitioners, physician assistants, nurses, social workers, psychologists, physical therapists, occupational therapists, speech therapists, registered dietitians). 90% of the behavioral and psychological symptoms can be effectively managed with psychosocial environmental interventions rather than psychiatric medications. Many people in terminal stages of dementia die with feeding tubes in place and with their wishes (advance care directives) not respected. This is inhumane. On the other hand, many patients who have dementia do not receive necessary interventions (e.g, surgery to treat bowel obstruction) because "they have dementia"! This is also inhumane. Education of health care providers (especially physicians) is critical to stop such inhumane practices.

4. Development of appropriate services for people who have dementia and their family and professional care-partners (caregivers, carers). 90% of the suffering of patient and their family members can be avoided by providing these services starting early and maintaining them throughout the course of the illness. Maintaining connections and communication with people who have dementia through creative engagement and other activities and innovative programs should be routinely available. We are seeing people who have dementia responding to highly-individualized care in the way that we wouldn't have believed. We can even see some improvement in dementia and often see leveling out of the deterioration. ***One of the main the priorities from public health perspective is to keep people in their homes and supporting family members to keep the person who has dementia at home.***

Individuals prefer to share a new or threatening experience with others and this increases their chances of being reassured and supported. Sharing caring experiences with others in a similar situation reduces the level of ‘burden’ and enhances quality of life for patients as well as care-partners (caregivers). The advice and support given to a family member at an early stage in the dementia trajectory promotes the psychosocial well-being of both the care-partner and the person who has dementia. Thus, support and advice are key to improving quality of life of people who have dementia and their family, particularly if such interventions include some type of informal or formal group work.

Appropriate services for people who have dementia and are living in assisted living or nursing homes involves ensuring wellbeing of front-line staff members (e.g., certified nursing assistants). relationship with staff is the most important factor influencing quality of life of long-term care residents. Ensuring adequate education, training, ongoing mentorship, appreciation and respect from all team members, leadership opportunities and appropriate work-load for LTC staff will improve quality of life of residents more dramatically than any other strategy.

5. End-Of-Life (EOL) Care: There are two assumptions that negatively influence EOL care. One is that poor quality of life is necessarily part of dementia, and the second is that people with dementia don’t always need active palliative care. ***A major barrier to high quality EOL care is the belief that because patients’ cognitive capacities (e.g., memory, language) are not functioning, therefore, feelings (emotional and sensory) are not experienced and spiritual needs are non-existent.*** In fact, many consider people with severe stages of dementia as already dead (a concept termed ‘social death’). So family and professional caregivers may not be aware of or may not believe that patients who have dementia can benefit from all the important principles that we have in palliative care (e.g., emotional and spiritual wellbeing, relief from pain and suffering) and the idea that there can be quality in end-of-life experiences!! It is often assumed that the brains of people who have dementia are shot! That their awareness and sensitivity and feelings are gone. This is reflected for example, in a staff making a statement that “Isn’t it just as well that the patients don’t have any awareness of where they are and what’s going on?” People who have dementia can feel until the last second of their lives!! And the awareness of death is not necessarily something that goes in a person who has dementia. Conversation about death and dying with persons having dementia is not only okay but in many situations is necessary. Family and professional care-partners (caregivers) should be encouraged to respond to such preoccupation and not deflect them.
6. Research: A substantial increase in funds to support research to identify psychological (e.g., support groups, individual psychotherapy), social (e.g., brain-enrichment programs, adult day programs), cognitive (e.g., interpreting non-verbal communication of persons with severe cognitive impairment, using art to improve communication), and environmental (e.g., improved resources for transportation) is necessary to identify interventions that are cost-effective and help patients live in their homes for as long as is possible, reduce suffering and improve their quality of life. By spending 99% of research funds on finding the “magic cocktail” to “fix” Alzheimer’s disease or to do costly brain imaging studies, the research community is sending a message to health care professionals and lay people that we do not care for the suffering of people who have dementia and their family members.

**Conclusion:** The government can play a key role in dramatically improving the quality of life of people who have dementia and their family members by committing to these six step approach and supporting it with adequate investments. I have learnt much from my many patients. One patient who was extremely fearful that she would develop Alzheimer's disease because her mother had AD wrote this "Why me?" letter after being diagnosed with Alzheimer's disease. We need to realize that our patients and family members are extremely resilient but they need help and support from all aspects of the community – the government, the health care professionals, the Alzheimer's Association and many other not-for profit and for-profit organizations. We all need to work together in partnership to make this happen.

### **Why me?**

The caterpillar doesn't argue that it would rather be a butterfly. It simply submits to the plan that God created for it and curls up inside the cocoon when the time comes for the miracle to take place. And what a miracle it is. When the transformation is complete, a different creature – different in form and different in abilities – emerges from the cocoon and flies away to begin its new life with wings.

In his mercy, God transforms you as well – if you let him. He exchanges your impatience for grace and your anger for compassion. After his work is complete in you, you emerge as someone better than you were before. With God's love and grace inside you, you, like him, become slow to anger and quick to love.

### **References and Recommended Resources**

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3. National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) has issued a joint dementia guideline available on the NICE website at <http://www.nice.org.uk/CG042> and the SCIE website at <http://www.scie.org.uk>
4. Guidelines for dementia care. National Health Service in Great Britain. 2006. <http://www.medicalnewstoday.com/articles/57308.php>
5. Marshall M. Example of good practice in the continuum of care: A report. European Alzheimer Clearing House, 1998. <http://www.each.be/introduction/WP2/GoodPractices.htm>
6. Mary Marshall of the University of Stirling (Scotland) gave the opening address at the AlzEurope conference in 1999. Innovations in End-Of-Life Care, June-July 1999; 1(4). [www.edc.org/lastacts](http://www.edc.org/lastacts) Excerpts from the interview can be found at: <http://www2.edc.org/lastacts/archivesJune99/intlpersp.asp>
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8. Healthy Brain Aging: Evidence based methods to preserve brain function and prevent dementia. Special issue with 11 articles. Clinics of Geriatric Medicine. February 2010.
9. Grossberg GT, Desai AK. Management of Alzheimer's disease. Journal of Gerontology and Medical Sciences. 2003;58A(4):331-353.
10. Desai AK, Grossberg GT. Psychiatric consultation in long term care: A guide to healthcare professionals. The Johns Hopkins Press. In Press.
11. Goldsmith M. Hearing the Voice of People with Dementia. London: Jessica Kingsley, Publishers, 1996.

### **Important models to learn from:**

1. Models of care developed by Dementia Services Development Center (DSDC) at the University of Stirling, Scotland, an internationally renowned center for dementia research, training and service development.
2. Wisconsin Alzheimer's Institute's model to improve early diagnosis and treatment in primary care throughout Wisconsin.
3. Several models adopted by Scandinavian countries where the greatest improvements are being made in the care of people with dementia. In these countries, the investment in staff training, staff development and new models is very considerable and remarkable. For example, small domestic models of care, which are highly person-centered, are the norm in Sweden, Denmark, Netherlands and Finland. These countries have great day care and ever increasing home care. Some countries (e.g., Finland) have completely transformed the level of care in just 7-8 years. All of them have moved away from big nursing home – bulk care models that are still the norm in U.S. The reason for their success is support from the highest level of the government and investment by the government.

## **My name is not dementia: People with dementia discuss quality of life indicators**

April 2010

First published 2010 by Alzheimer's Society  
London

Excerpts from this document.

People with dementia often feel that dementia becomes the only thing others know about them. But they remain individuals in their own right and dementia is not the most important thing about them. Many are still able to do what they did before despite their life changing and some things becoming increasingly difficult to do. ***The ability to lead a fulfilled life doesn't stop on diagnosis. A good quality of life can be maintained and that is what this report will help us to understand.***

Ruth Sutherland  
Acting Chief Executive

## **Foreword by Sir Terry Pratchett**

### **Out of the shadows, blinking in the light**

People are frightened about the future. And, because the baby boomers don't like being frightened, they tend to get angry too. They are ready to believe stories about someone's relative's treatment in a not very caring 'care home', they see in documentaries the hopeless elderly vegetating in chairs, they read Sir Michael Parkinson's vehement attack on the waiting

rooms for death. They are not as compliant as their ancestors who went through a world war, and suddenly we find a growing interest in assisted dying. Fear is the spur, fear of hell before death. It is a tragedy that this is so, and a tragedy, too, that sometimes their fear is well founded. The care industry has a lot of work to do. ***Dementia is all too often a fact of life, and no longer out of sight and out of mind. And it requires not just care but also understanding and, to be frank, policing as well.*** There is an opportunity here to give the lie to some of the clichés of care. We have to learn to be good at it.

Thank goodness for Alzheimer's Society.

I commend this report.

Terry Pratchett OBE

Author

## Executive summary

Consistent themes emerged from the research about what was important in people's quality of life and the methodology proved successful enough to indicate that it could be used on a much bigger scale, with some refinements, to gather information about quality of life, especially from people with more severe dementia.

***The key quality of life indicators and findings, in order of importance, that came out of the research were:***

- 1. Relationships or someone to talk to***
- 2. Environment***
- 3. Physical health***
- 4. Sense of humor***
- 5. Independence***
- 6. Ability to communicate***
- 7. Sense of personal identity***
- 8. Ability or opportunity to engage in activities***
- 9. Ability to practice faith or religion***
- 10. Experience of stigma***

## Overall findings about quality of life arising from the project

Four overall findings emerged from this project.

1. People with dementia, including people with more severe dementia, are able to express their views about what is important to their quality of life.
2. The domains that feature in generic quality of life measures may be of just as much relevance to people with dementia, including those with more severe dementia, as the more dementia-specific domains in health-related quality of life measures for people with dementia.
3. ***Maintaining a good quality of life is perfectly possible following a diagnosis of***

*dementia. Services for people with dementia, and the wider community, should not make assumptions that following a diagnosis of dementia support to improve a person's life is pointless because it will have no impact on quality of life. There are many factors outside a person's dementia that affect their quality of life and this indicates that services should develop so that they can address these wider quality of life issues. Despite being a progressive, terminal condition that severely affects a person's mental functioning, dementia may not affect a person's quality of life in respect to emotions, feelings and mental well-being in ways that one would expect. Quality of life is defined primarily by the person, as a person, and their circumstances, not their dementia.*

4. People with dementia have a clear need for regular, everyday, one to one social interaction and this will have significant benefit to their quality of life and social inclusion.

**Carolyn McLaren's Submitted Testimony on Behalf of the**  
**Missouri Association of Area Agencies on Aging (M4A)**

**ALZHEIMER'S TESTIMONY**

**Representative from MA4**

**Carolyn McLaren**

**May 27, 2010**

Thank you for allowing me to speak to you today, I represent MA4, the Missouri Association of Area Agencies on Aging. We are comprised of the ten Area Agencies across Missouri. MA4 provides essential services on the local level everyday that maintain the quality of life, health and social connections for Missouri Seniors. We are an expert on the issue of aging and are uniquely qualified to be the leading statewide advocate and local provider of vital information for Missouri Seniors. We not only focus on the needs of today's seniors, but understand and plan for the changes that will take place in the aging population as the baby boomers begin to turn 65.

We appreciate the opportunity to tell you what we are seeing across the State. We are finding more requests for services for persons with early on-set Alzheimer's, many of these below the age for Area Agency on Aging services. People are struggling to keep their loved ones home as long as possible in spite of reduced or no services. We see seniors with Alzheimer's outliving their family or having long distance caregivers; this leaves them very alone and vulnerable.

The problems we see for caregivers are numerous. Many caregivers are as old as or older than the person with Alzheimer's. Frequently the caregiver themselves have chronic and sometimes disabling conditions. Many caregivers do not keep up with their own health issues because they have no one to care for their loved one while they take care of themselves. We have seen the caregiver pass away before the Alzheimer's victim or burnout becomes a huge issue and caregivers become abusive or just walk away.

For the caregiver that is forced to leave a job to care for a parent or spouse they lose more than an income, they may lose their insurance benefits as well. The loss of benefits can be devastating. One of our staff remembers a caregiver who did not take necessary heart medication because they could not afford it without insurance. Also a caregiver who was ignoring a lump in her breast because she had no insurance and was terrified of the cost of treatment, of course the case worker referred her to a program that helped her, but just the insecurity of not having health benefits kept her from seeking treatment. Both of these women had left jobs to care for their loved ones and were not on disability or were eligible for any other assistance.

Other issues are limited financial assistance for in-home service such as personal care and respite, legal needs such as guardianship where funds are not available to pay a lawyer and court costs, nursing and assisted living facilities with no "memory care units", and lack of Day Care facilities that are geared toward dementia clients, programs that supply respite and other services but have waiting lists.

When we look at what is working for our clients we see programs that help with supplemental supplies, respite and case management, information and education, all are of great value to caregivers. Our clients are so thankful and appreciative when we provide these services. There have been instances when supplemental supplies have made such a difference in peoples lives. One of our case workers recently had a client who was caring for a diabetic father. He suffered from skin break down in the hip region. They could not afford incontinent briefs, the lack of which was contributing to his skin break down. The case worker was able to provide incontinent briefs and wooly bed pads to aid healing. The client called back about two weeks after receiving her supplies and reported that her fathers skin break down was finally beginning to heal for the first time in a long time. Last summer, a series of caregiver classes were provide which included respite care for the participants. One gentleman attended every class, he did not say much during the classes. However, after the last class, he stopped the presenter, put one hand on her shoulder and simply said thank you, but the look in his eyes and the tone of his voice spoke volumes.

Partnering with other organizations such as the Alzheimer's Association to make the best use of services, supplies and information and referral to each program is a great asset to all of the organizations working to help Alzheimer's clients and their families.

The question "What do we see as solutions?" is a very challenging one. Of course more funding is one response. We need more funds for "Memory care units" in nursing and assisted living facilities, more funds for respite, personal care, and Day Cares. We need to continue to work together sharing information and working on grant funding for services. There are also a huge number of new technological solutions to assist caregivers that should be evaluated and made available if possible. And very importantly we must ask our caregivers what they need.

Thank you for giving me the opportunity to share our observations, concerns and recommendations with you today.

## **Missouri Alzheimer's Disease State Plan Task Force**

### **Summary of Comments from Five Statewide Community Forums**

The Alzheimer's Disease State Plan Task Force held five community forums from January to April 2010 to hear from the residents of Missouri about what their thoughts and concerns were in regards to living with Alzheimer's in the state. The five forums were held in Columbia, St. Louis, Springfield, Cape Girardeau, and Kansas City. In a review of the forum notes, the following themes emerged.

#### **Caregiver Stress**

Comments concerning the stress placed on caregivers focused on how Alzheimer's does not affect just the person with dementia but also the physical, mental, social, and financial well-being of the caregiver.

##### *Job-Related Stress*

The most frequent comment under Caregiver Stress had to do with the caregiver's need or inability to remain in the workforce while also caring for their loved one. Some workplaces were flexible in allowing time off for caregiving while others were not flexible. The responsibility of caregiving forced many to quit their jobs, and others wanted to quit but could not give up the insurance or benefits. One caregiver pointed out that even after her parents passed away, it has been difficult to reenter the workforce because of the large gap in her work history. Another person remarked that caregivers not only lose income from not working but also lose social security credit for retirement.

##### *Medical Effects*

Stress was linked to medical illnesses, exhaustion, and even death. As one person shared, the stress her father experience while caring for her mother led to his death. It was suggested that there is empirical research to support this and that the issue deserves greater attention.

##### *Stress from Legal, Financial, and Social Burdens*

Legal issues, including obtaining guardianship or establishing power of attorney, were cited as sources of stress. One caregiver brought up the "double whammy" of trying to establish guardianship for her mother who has dementia and transferring guardianship of her mentally retarded sister from her mother to herself. Caregivers felt socially isolated and abandoned by former supports, and there was stress related to the cost of care.

#### **Services and Resources**

##### *Existing services and resources*

The most frequently mentioned resource was the Alzheimer's Association and the Association's programs, including Care Consultations, early stage programs, support groups, and respite. The majority of comments were positive towards the organization, but a few caregivers felt that they were not given enough assistance. The Area Agencies on Aging, elder law attorneys, and the Boone County Resource Directory of Senior Services were also mentioned as useful resources and services. Concerns about budget cuts and waiting lists were voiced about some services and resources.

### Getting a Proper Diagnosis

Getting a doctor to give an Alzheimer's diagnosis was sometimes referred to as a fight. There were several stories about being misdiagnosed for several years with a variety of disorders, including depression or adult attention deficit disorder, and there were even doctors who did not believe in Alzheimer's disease. As one person said, a diagnosis of Alzheimer's disease after years of misdiagnoses was a relief because "you can't start living until you have a diagnosis and you know the problem you are facing." Some people were given a diagnosis of Alzheimer's disease when it was really something else, such as medication related.

### Respite

Comments about Respite focused on its importance to caregivers, the need for more funding, and the barrier of long waiting lists for both the Alzheimer's Association and Area Agencies on Aging respite programs. Participants also noted that while it was important, the time given to caregivers was minimal and they could use more than just a few hours each month. One volunteer for the Alzheimer's Association Helpline call center said that the number one call they receive is for respite care.

### Rural Services

The lack of resources in rural areas was often mentioned as a barrier. Having to travel to more metropolitan areas to get appropriate services was one of the factors.

### Waiting Lists

When appropriate or quality services existed, there were often long waiting lists that acted as a barrier. Waiting lists were often cited as barriers to respite care and admittance into assisted living facilities.

### Other Barriers

Other barriers included the availability of in-home care workers, services for people with early stage Alzheimer's disease, and case management. In Kansas City, MO, there was comparison of services and quality between the states of Kansas and Missouri, including a lack of memory care in assisted living for those living on the Missouri side.

### **Cost of Care / Paying for Care**

The cost of care was frequently mentioned, and as one participant summarized it, "this disease costs more than most have ever had to pay for anything in their life." A few caregivers cited costs of care as high as \$250,000 over 5 years and \$70,000 a year.

### Cost of Keeping People at Home

Comments frequently focused on the cost of keeping a loved one at home and the need for assistance to do so. These comments typically framed the cost of caring for someone at home as more cost-effective than nursing home placement and encouraged the state to provide more assistance for in-home care and for family caregivers.

### Drugs and Other Costs

The cost of prescription drugs was often cited as a burden. Financial assistance for home medical equipment and the cost of seeking needed legal assistance were also mentioned.

### Medicaid and Medicare

Participants talked about falling just above the income limit to qualify for Medicaid or being forced to spend-down. Once on Medicaid, it only covered nursing homes and not assisted living or in-home care. Medicare was referenced particularly in relation to the cost of medications in the doughnut hole of Medicare Part D, the hospice benefits, and the homebound restrictions.

### Healthcare and Long Term Care Insurance

When people mentioned their health insurance plan, it was typically about how fortunate they were to have one or how they needed to keep working to maintain the plan. Long term care insurance (5) was referenced in terms of how much it costs, the restrictions on what it covers, including a 3-year limit and only nursing home care, not assisted living, and that there should be an employer tax incentive for offering long term care insurance.

### **Quality of Care / Professional Training**

The Quality of Care covered a range of comments about existing high quality services and the need for higher quality in other areas. Increasing the quality of care and responding to the individual's needs were cited as improving the outcomes for the person with dementia. A number of participants expressed a need for more or better professional training across the care continuum, including how it should be mandatory.

### Medical Community

Doctors, the medical community, and hospitals were often cited as needing more training in working with persons with Alzheimer's and other dementias. While doctors needed to be better trained in diagnosis, they also needed to know how to better interact with persons with dementia and to know how to refer patients and caregivers to resources. There was a feeling that the diagnosis came without any hope for what could be done.

Some participants explained that doctors and hospital staff would often try to collect information from the person with dementia when they could have consulted with the caregiver to get more accurate information. There were suggestions that this training should be a part of medical school training.

### Staffing Quality

The quality of in-home care and long term care facilities was often related to the need for more staff, including lower staff to resident ratios, and better trained staff. While staff who work with persons with dementia are required to receive training, there were comments on how the quality of that training is monitored.

### Long Term Care Facilities and In Home Care Workers

Comments about long term care facilities and in home care workers included that they did not know how to approach and work with persons with dementia and that more training was required. A suggestion of monthly in-services was given.

### Hospitals

There were comments and stories about how hospitals are not prepared to work with persons with Alzheimer's and how this can negatively affect the health of a person seeking care in a hospital. As one person noted, the hospital trips actually made her loved one's health decline more rapidly. Some of the suggestions included that hospital staff be trained in dementia care, a dementia care specialist be on staff at the hospital, or the person with dementia have a care history record that travels with them from the long term care facility to the hospital.

### Regulations and Standards

Statewide regulations for special care units and staff trainings were recommended. Also, making it easier for families to know how well a facility scored in state inspections was important in selecting quality care. One participant compared it to health department ratings of fast food restaurants, asking why should the quality of long-term care facilities not be just as easy to know.

### Veteran's Homes

At least one person at each of the forums mentioned that their loved one was in a Missouri Veteran's Home and that the quality of care they received there was excellent. There was concern that all care facilities should have this same level of person-centered care.

### **Public Awareness / Education for Individual**

Many participants made comments that there needed to be great public awareness about Alzheimer's disease and that families needed to be better educated on the disease and the resources available.

### Family Education

According to many of the participants, individuals with Alzheimer's and their families needed more education on the progression of the disease and what resources were available to them. Information on long term care facilities, medications, and legal advice were all areas where there needed to be greater education and awareness among families.

### Public Awareness

Participants cited that until they had Alzheimer's in their family, they knew nothing about it. It is still not talked about. As one participant said, we do not have a face for Alzheimer's, and even in a newspaper article that day on "The Face of Alzheimer's," the accompanying photo was of someone's back as they walked away. There was a sense that all Missourians should be aware of Alzheimer's and its impact.

### **Research**

The need for research or the hope that there would someday be a cure was frequently mentioned. Typically, the statement focused on the need for more research funding. There were also comments to lift restrictions on research, recognizing the work of the Alzheimer's Disease Research Center of Washington University in St. Louis, and to increase research outside of these metropolitan areas.